8-1-1991

Reasons Community-Based Hospice Patients Require Hospitalization

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REASONS COMMUNITY-BASED HOSPICE PATIENTS REQUIRE HOSPITALIZATION

by

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A Thesis
Submitted in partial fulfillment of the requirements
for the Degree of Master of Science in Nursing
in the Division of Nursing
Mississippi University for Women

COLUMBUS, MISSISSIPPI

AUGUST, 1991

ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 - 1346

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Dedication

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10-26-1919 to 12-17-1974

With love and appreciation, I dedicate this research study to my father. He taught me the value of higher education and offered support and encouragement. Although he did not live to see my accomplishments, I know he is proud.

Daddy, this is for you.

Acknowledgements

I am very thankful for the assistance of my Research Committee for their continual guidance and suggestions. The patience, encouragement, support, and expertise of Dr. Maripat Curtis, Thesis Director, and Dr. Linda Olivet are greatly appreciated.

Special thanks are offered to the Board of Directors of Hospice of West Alabama for their cooperation afforded me in data collection.

Much love and appreciation go to my husband Lackey for his patience, understanding, and love during this study. His faith in me and constant encouragement were the driving forces behind the completion of this research.

Abstract

The philosophy of a community-based hospice program involves care of terminally ill patients in their homes. However, some patients do not remain at home and are hospitalized. This descriptive study was conducted to determine reasons community-based hospice patients require hospitalization. Orem's Theory of Self-Care and Theory of Nursing Systems provided the theoretical framework.

A convenience sample of 9 hospice patient primary caregivers from a community-based hospice program in West Central Alabama participated. These caregivers provided care to 9 hospice patients over the age of 40 years who required hospitalization in 1990 and had since expired. During scheduled home interview visits, the researcher completed the Stephens Survey of Hospice Patient's Primary Caregiver tool to determine reasons for the patient's hospitalization. The taped interviews were transcribed and reviewed by the researcher and two nurse experts. Quantitative data were analyzed using descriptive statistics. Qualitative data were evaluated by content analysis.

The researcher concluded that uncontrolled pain was the most common cause for the patient's hospitalization. Also, interview analysis revealed two categories which amplify why patients were admitted to the hospital: caregiver stressors/demands and relationships with health care providers. In the roles of counselor, educator, and consultant, the Geriatric Nurse Clinician can assist patients/primary caregivers and other care providers to apply findings of this study to the development of policies, programs, and procedures to more effectively manage the pain of terminal illness and the stressors associated with caregiving. Recommendations for future study include conduction of research related to patient/primary caregiver teaching compliance and responses to pain management in hospice patients and also replication of the study with a larger sample and further instrument development.

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Chapter I

The Research Problem

The philosophy of a community-based hospital program involves the care of terminally ill patients in their homes. If the patient so desires, home care is maintained until the patient's time of death. While the hospice philosophy emphasizes palliative home-based care that involves the patient's family, home death is by no means a requirement (Mor & Hiris, 1983). Some hospice patients are unable to be managed with home care and require hospitalization.

The concept of hospice care is relatively new in the United States. Therefore, research is limited particularly in the area devoted to reasons hospice patients require hospitalization. This present study focused on the reasons why community-based hospice patients require hospitalization in order to aid the future direction of hospice nursing interventions and plans of care.

Introduction to the Problem

Hospice is a comprehensive program of management that offers an opportunity to provide palliative care for terminally ill patients in their home (Zimmerman, 1986). Palliative care involves interventions that focus primarily

on reduction or abatement of physical and psychosocial symptoms of terminal illness. A patient is considered to be terminally ill if suffering from a disease that has a prognosis of 6 months or less (National Hospice Organization, 1981).

One of the goals of a hospice program is to maintain home care of the terminally ill patient. McDonnell (1986) concluded, after reviewing numerous research studies, that both the patient and family preferred to have the patient at home for as much of the terminal illness as possible. Kalish and Reynolds (1976, cited in Mor & Hiris, 1983) found that over 50% of a sample of middle-aged persons reported that they would prefer to die at home. Advocates of the hospice movement reported that when given the choice, patients and families preferred that death occur in the familiar surroundings of the home (Dubois, 1980; Stoddard, 1978). The freedom from institutional restrictions and open access to family and friends make the home setting more comfortable for the patient. However, if the necessary support services are not provided or if other factors influence the disease course and patient/family unity, hospitalization of the patient may occur (Zimmerman, 1986).

The vast majority of patients admitted to a hospice program have a diagnosis of terminal cancer (Zimmerman, 1986). The diagnosis of cancer affects the entire family system by generating great anxiety, which may alter

communication patterns, role expectations, and family relationships (Lewandowski & Jones, 1988). These alterations may apply to all terminally ill patients in hospice care. These crises may cause confusion for both the patient and family. If the alterations lead to the hospice patient's hospitalization, this may conflict with the patient's desire to remain in the home and add further stress and disequilibrium to the illness as well as impede communication (Zimmerman, 1986).

Additional crises with role expectations may develop. The caregiver's concerns and fears of impending death become magnified as the daily decline of the patient is observed (Rosenbaum & Rosenbaum, 1980). Many family caregivers fear being alone with their loved one when death is imminent and fear their judgements or actions may be inappropriate and/or hasten death (Donovan & Girton, 1984). At the same time, the patient may feel like a burden to the caregiver/family and fear rejection by these individuals. The patient may believe that a dying person does not make very pleasant company and that the very imminence of death, as well as an intolerable or repugnant physical condition, may repulse even the intimate family (Strauss, 1975). Also, the stress of home care may raise already elevated tensions to the point that the patient is barely tolerated by the family so that increased strife occurs (McDonnell, 1986). Rando (1984) stated that family members may even begin to resent

the emotional, economic, and time resources spent on the dying patient because little time is left for the family to gratify their own needs. The patient dying at home typically focuses strongly on the companionship of one family member and may not wish to see any other members except for brief moments. This attachment is comforting to the patient but may be a difficult relationship for the caregiver (Strauss, 1975).

Numerous other presenting symptoms of terminal illness provoke crisis in home care. Zimmerman (1986) found that the single most common reason for the hospice patient's hospital admission was inadequate pain control. Other authors noted that increased or uncontrolled pain was a major factor in the precipitation of a family crisis (Christensen & Harding, 1985; Morris et al., 1986; Rando, 1984).

Confusion, restlessness, agitation, insomnia, nausea, and vomiting were noted as frequent problems faced by hospice home patients. "An uncomfortable, sleepless patient sups the strength of the others in the household; this may be the factor that tips the balance against the patient remaining at home" (Zimmerman, 1986, p. 280).

If the hospice patient indeed requires hospitalization, the type of hospice organization providing care has a major impact on continuity of care. If the patient is admitted to a "hospital-based" hospice program of care, the problem of

hospitalization is lessened. Hospital-based hospices offer hospice in-patient care as a part of their service. However, community-based hospice programs do not offer hospice in-patient services.

Most community-based programs have no control over the patient's care once the patient enters the hospital (Davidson, 1985). This fact can make it more difficult for the patient and family in the decision to admit the patient to a hospital setting. Because this present study is based on the reasons community-based hospice patients require hospitalization, the lack of continuity between community-based hospice programs and hospital care was considered.

When the community-based hospice patient's home plan of care is interrupted by hospitalization, the loss of continuity of hospice care may occur. The familiar home surroundings are lost and the patient's and family's medical, emotional, and spiritual needs may not be addressed in the hospital setting in the same way as in the home setting.

Americans assume that the hospital is the place to die; it is equipped to handle the medical complications and burdens of the last hours of life (Strauss, 1975). This tendency to hospitalize may contribute to the impediment of palliative care to patients for whom no cure is known (Zimmerman, 1986).

As medical services and technology have advanced, the climate in most hospitals has become complex, dehumanized, and cure-oriented. "Considerable and inevitable philosophic conflict exists when critical, life-prolonging care and palliative, symptom-controlling, life-enhancing care are combined within the same institution" (Donovan & Girton, 1984, p. 126). Therefore, hospitalization presents problems for both the patient and family.

When hospitalized, the patient is removed from the familiar home surroundings, and too often family members remove themselves from the patient to avoid acknowledging the fact that they too will die some day (Rando, 1984). Even if the family members choose to remain close to the terminal patient, in many hospital situations kinsmen are put in a waiting room and are forbidden to be with their loved one at the time of death. In a hospital, all family members are considered outsiders (Donovan & Girton, 1984). The relatives may be told that their presence is too stressful for the patient, who "must rest" as death progresses, and this leads to the patient being surrounded by strangers at the time death occurs (Strauss, 1975).

The need for hospitalization may not be a reflection of the desires and needs of the patient and may address only the needs and desires of the family. This confusion may precipitate increased patient and family mental and physical

stressors, particularly if the patient wishes to return and die at home and the family cannot support this desire.

Knowing the reasons community-based hospice patients require hospitalization may uncover unmet patient and family needs and stressors. This information can guide the hospice nurse in planning appropriate preventive interventions that may alleviate the need for the patient's hospitalization. Therefore, a descriptive study to describe the reasons community-based hospice patients require hospitalization was implemented.

Significance to Nursing

Terminally ill patients and their families need symptomatic and supportive management and must be taught the skills necessary for self-management of home care related to the dying process. The Geriatric Nurse Clinician (GNC) working in a hospice setting is in an excellent position to offer this management through assessing, directing, guiding, and implementing patient care. In addition to physical support and education, the nurse clinician can offer psychological, psychosocial, and spiritual support to the patient and family. Also, the nurse clinician has unique qualifications and may implement and/or coordinate an interdisciplinary team approach to meet these demands.

Because scant research exists involving the needs of hospice patients and families, the nurse clinician is in an excellent position to conduct new research based upon

patient/family needs and plans of care which could lead to further theory development in nursing and the advancement of nursing knowledge. The nurse clinician's provision of increased knowledge could serve as a model for hospice care and greatly increase the quality of hospice home care. Increased quality of home hospice care by the nurse clinician may reduce the need for the patient's hospitalization.

Theoretical Framework

Orem's Theory of Self-Care and Theory of Nursing Systems and their interrelationships was incorporated into this research. These two theories related to hospice home care and hospitalization of the hospice patient.

Theory of Self-Care. Orem's Theory of Self-Care proposes that "a relationship exists between deliberate self-care actions and the development and functioning of individuals and groups" (Meleis, 1985, p. 284). Self-care is defined as the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being (Orem, 1980). This self-care can be performed directly by the individual or it can be care that is provided to that individual by another person. Hospice is a program that can offer assistance with self-care by providing palliative home care for terminally ill patients (National Hospice Organization, 1981). The hospice nurse works directly with the patient and the patient's

primary caregiver to promote self-care and meet the patient's self-care requisites.

Orem (1980) stated that individuals have certain self-care requisites, based on their self-care demand. These self-care requisites include universal, developmental, and health-deviation needs. Self-care demands are defined as the measures of care required to meet existent requisites in order to maintain or promote health and general well-being (Marriner-Tomey, 1989).

The purpose of self-care is for the patient's attainment of universal, developmental, and health-deviation self-care requisites. The patient requiring hospice care has a developmental self-care requisite. Orem (1980) defined one of the developmental self-care requisites as the provision of care either to prevent the occurrence of deleterious effects of conditions that can affect human development or to mitigate or overcome these effects from conditions such as terminal illness or impending death. The hospice nurse develops a plan of care with and for the patient which attempts to allay the physical, mental, and spiritual distresses of terminal illness and meets the patient's self-care requisites. If the hospice nurse can assist the patient with self-care requisites, home care can be maintained and hospitalization can be avoided.

Theory of Nursing Systems. Orem's Theory of Nursing Systems "describes therapeutic self-care requisites and the

actions or systems involved in self-care" (Meleis, 1985, p. 285). The nurse assists the patient through nursing actions. Nursing care is considered therapeutic self-care if the patient cannot perform this self-care. Orem (1980) stated that the nurse provides any or all of these three levels of care:

1. Wholly compensatory: The nurse provides all of the patient's self-care measures.

2. Partially compensatory: The nurse and the patient provide self-care measures.

3. Supportive-educative: The nurse assists the patient with decisions, behaviors, and skill/knowledge attainment.

The hospice patient requires partially and wholly compensatory care due to the nature of terminal illness. A patient may enter a hospice program of care at the partially compensatory level, remain there, or digress to the wholly compensatory level as the disease progresses. Nursing care is adjusted to compensate for this decline in the level of self-care.

If hospice home nursing care and patient self-care are successful, the patient may be able to remain at home throughout the illness and die in this same environment. However, the patient's self-care demands and deficits may interfere with home care and require hospitalization of the patient.

Assumptions

The following are assumptions of this study:

1. The patient's primary caregiver has the capacity to recall information related to the patient's hospitalization.

2. Hospice care can support the patient in the home environment to reduce the need for hospitalization.

Statement of the Problem

Hospice is a relatively new concept in the United States. Due to the lack of previous research related to the hospice patient's hospitalization, this researcher wished to know the reasons for the community-based hospice patient's admission to a hospital.

Research Question

The question this study sought to answer was what are the reasons, as cited by primary caregivers, for the hospitalization of community-based hospice patients?

Definition of Terms

For the purpose of this study, the following terms are defined:

Reasons: Any personal or physiologic reaction(s) experienced or demonstrated by the patient or primary caregiver that may have interrupted home care and led to the patient being hospitalized. Operational Definition: The reactions noted by the primary caregiver on (a) the Stephens

Hospice Patient's Primary Caregiver Interview Form and (b) the Stephens Hospice Medical Record Information Form.

Community-based hospice patient: A patient receiving care from a hospice organization that is not affiliated with or operated by a hospital (McDonnell, 1986). Operational Definition: A terminal patient admitted to a West Alabama hospice program who required hospitalization in the year 1990, has since expired, and was 40 years old or older.

Hospitalization: The return of a hospice patient to a hospital setting after he/she has been admitted to a community-based hospice program of care. Operational Definition: The hospital admission of a West Alabama hospice patient to one of two local hospitals located in Tuscaloosa County.

Primary caregiver: The person designated by the patient to provide emotional support and/or physical care to the patient (National Hospice Organization, 1981). Operational Definition: The person noted on the hospice admission data form as the individual responsible for the patient's home care.

Chapter II

Review of the Literature

This literature review revealed limited research related to hospice care, and no research could be located that dealt specifically with the reasons hospice patients require hospitalization. The following review concentrated on research studies that related to the subject areas of patient symptomatology of terminal illness and patient and caregiver stressors related to home care of terminal illness and concludes with studies related to the role of the health care provider involved in terminal care.

Patient Symptomatology

Watchtel, Masterson, Reuben, Goldberg, and Mor (1988) studied data collected for the National Hospice Study (NHS) of 1981-1983 to emphasize a temporal relationship of the progressive increase in physical symptomatology with the parallel decline in function and quality of life related to terminal illness. Forty hospices and 14 conventional care settings participated in the NHS. These institutions were located nationwide.

Data were collected by interviews with patients and their primary caregivers (PCG) at the time of entry into the

hospice program and every 2 weeks thereafter until the patient's death. The last measure took place within 14 days of death. Twenty-nine percent of the initial interviews and 64% of the final interviews were conducted with only the PCG due to the patient's advanced disease state and inability to participate in the interview.

A total of 1,754 patients were included in the sample; 1,119 patients were included in the analysis. Of the 1,119 patients, 609 lived long enough to have three interviews conducted before death occurred. Data were presented by both primary cancer type, location, age, and sex. Thirty-five percent of the subjects were 21-64, 41% were 65 to 74, and 24% were over 75 years of age. Fifty-three percent were female. The most common types of cancer were lung, breast, and colorectal.

The study focused on the following symptomatology: pain, shortness of breath, fever, nausea and/or vomiting, constipation, diarrhea, weight loss, and problem eating/poor appetite. Results revealed that each of the above symptoms was present in relatively high prevalence within 4 to 6 weeks prior to death and did not increase much as death approached. The prevalence of fever, dyspnea, anorexia, and weight loss increased 12 to 15% during the period of observation while the other symptoms changed very little. It should be noted that only prevalence of symptoms and not severity was noted in this study.

Pain was more common 4 to 6 weeks before death related to the site(s) of malignancy. Dyspnea increased during this same time period and was related to the proximity of the malignancy to the chest wall. However, dyspnea was more common in patients over age 65 years.

The prevalence of fever was low and there was little difference related to the patient's primary cancer site or gender. Nausea and vomiting were more prevalent in women but did not increase during the last weeks of life. This problem was decreased in the 65- to 74-year-old patient. However, the problem did increase with patients whose cancer involved the gastrointestinal tract.

One half of the patients complained of constipation and one quarter experienced diarrhea. However, this had no correlation to age. At 4 to 6 weeks prior to death, constipation was a less frequent problem with colorectal, cervical/uterine, and bladder/kidney cancer.

Anorexia, eating difficulties, and weight loss affected the vast majority of cancer patients 4 to 6 weeks before death and increased the last 2 weeks of life. Gender and age had no bearing on these problems.

Data from the PCGs revealed that over 50% of all patients had full mental capacity 4 to 6 weeks prior to death. At 2 weeks prior, one third maintained full mental capacity.

Watchtel et al. (1988) concluded that only 4% of terminal patients were symptom free 4 to 6 weeks before death. They noted pain was a common symptom of terminal illness, and dyspnea was a more common symptom than previously noted. Nausea and vomiting also were common to 62% of terminally ill patients in the last 4 to 6 weeks of life and was present 44% of the time prior to this period. Constipation was determined to be an expected symptom related to medications used for pain control. Anorexia and weight loss continued to be the most common symptoms of terminal illness. It was noted that the loss of mental faculties has important implications for PCGs because these patients are still able to participate in decision-making regarding their plan of care.

The results of this study, according to Watchtel et al. (1988), are important because they indicate the tremendous amount of supportive care necessary during terminal illness. The research findings are significant to the present research study in that physical symptoms were validated as a part of terminal illness. These symptoms may not be manageable for the hospice patient and/or caregiver in the home for either physical and/or emotional reasons. This inability to manage physical symptoms may lead to the hospice patient's hospitalization. The research study findings related to common symptomatology were important

also in the development of the Stephens Survey of Hospice Patient's Primary Caregiver tool.

Caregiver/Patient Stressors

Stetz (1987) conducted research to determine caregiver demands of a spouse with advanced cancer. Four research questions were proposed for this study:

1. What is the level of physical disability in cancer patients being cared for in the home by spouse caregivers?

2. What are the demands of caregiving as reported by caregivers?

3. Do caregiving demands differ with respect to level of physical disability in the ill spouse?

4. Do male and female caregivers differ with respect to reported caregiving demands?

This descriptive exploratory study involved a one-time, semi-structured, at-home interview with 65 spouses. The sample was recruited from home-care agencies in the Pacific Northwest. The Experience of Caregiver Interview Schedule was used to gather data, and information related to the caregiver's physical disability was measured through an observational measure, the Zubrod Scale. Content validity was established by review of the tool by three clinical specialists and by pilot testing. Content categories were identified and defined, and coding rules were established to place the gathered data into categories. Along with the researcher, two coders reviewed the data according to

specific criteria, and an interrater-agreement score was calculated.

This study identified nine mutually exclusive caregiving demand categories: managing the physical care, treatment regimen, and imposed changes; managing the household and finances; standing by; alterations in spouse caregiver's well-being and patterns of living; constant vigilance; unmet expectations from health care system; cancer itself; anticipating the future; and alterations in relationships with ill spouse. Seventy percent of caregivers experienced two or more caregiving demands. Sixty-nine percent of the caregivers reported managing the physical care, treatment regimen, and imposed changes as the most dominant demand. The second most frequent demand (39%) dealt with managing the household and finances and standing by. Twenty-two percent of the sample reported problems related to alterations in spouse caregiver's well-being and patterns of living.

Related to physical disability of the spouse caregiver, Stetz (1987) concluded that the same caregiver demands noted above were present and in the same order with the exception of unmet expectations from the health care system ranking second. The mean number of demands reported according to the level of the spouse's disability did not differ significantly.

Pattern of demands did differ by gender. Male caregivers reported managing the household and finances as the second most frequent (52.6%) demand. Female respondents reported standing by as the second most frequent concern.

The findings of this study further elaborated those previously reported in the literature regarding the demands of caring for a spouse with cancer in the home. Also, the findings validated the difficulty of managing the responsibilities of physical care, treatment regimens, and illness related changes for primary caregivers.

Blank, Longman, and Atwood (1989) conducted an exploratory descriptive study to identify perceived home care needs of outpatients receiving treatment for cancer and their caregivers. The researchers conducted the study related to their beliefs that patient home care needs should be defined so that health care providers can provide quality home care. Study questions were: What are the perceived home care needs (physical, psychological, and health services) of cancer patients receiving outpatient radiation therapy and/or biological response modifiers? What are the perceived home care needs (physical, psychological, and health services) of caregivers of cancer patients receiving outpatient radiation therapy and/or biological response modifiers? Are there differences between the perceived home care needs of patients and their caregivers? Neuman's general systems model was used as the theoretical framework.

A purposive sample of eight patients and their caregivers was selected from a Southwest Arizona cancer center. Two interview guides developed by Neuman were used to assess patient and caregiver stressors. Content analysis was used to evaluate the data.

The researchers noted three types of stressors: intrapersonal, interpersonal, and extrapersonal. The interviewed patients identified intrapersonal stressors that included treatment uncertainty related to the course of therapy and outcome, physical restrictions/role changes, anger/depression, and isolation related to his/her illness. The interpersonal stressor that was identified was lack of support for the illness. The extrapersonal stressor included transportation and financial problems related to the illness.

The second research question relating to the perceived needs of the caregivers included the same three levels of stressors. Intrapersonal stressors for the caregivers included treatment uncertainty, role conflict/worry/added responsibilities, fear of being alone, coping with the patient's situation, and guilt related to his/her level of responsibility of the patient's care. Interpersonal stressors included lack of support, non-mutual relationship with the patient, difficulties with activities of daily living of the patient, and lack of information concerning a particular circumstance. Extrapersonal stressors included

transportation and financial difficulties. Research question number three (Are there differences perceived by the patient vs. the primary caregiver?) revealed that the needs of each person were congruent with each other.

Blank et al.'s (1989) findings indicated that treatment explanations, assistance in coping with role changes, social support, transportation, and increased income are major concerns for both the patient and caregiver during cancer therapy. This study concluded that the nurse providing care in this situation must assist both the patient and family with the above noted stressors. No recommendations were given.

The research by Stetz (1987) and Blank et al. (1989) is relevant to the current study in that managing the patient's physical care, dealing with caregiver changes and personal needs, and patient and caregiver stressors may or may not impact on whether the primary caregiver chooses or encourages their loved one to be admitted to a hospital setting. Some of these issues were addressed in the development of the Stephens Survey of Hospice Patient's Primary Caregiver tool to determine if they were related to the hospice patient's need for hospitalization.

Health Care Providers

Hull (1989) conducted a research review to examine research studies that focused specifically on family needs and supportive nursing behaviors during the terminal phase

of a relative's cancer experience. The included studies focused on family needs or supportive nursing behaviors that impacted the adult family member's terminal stage of cancer in both the hospital and home setting.

The instruments used in the reviewed studies involved either a Q-sort or Likert-like scale. The Q-sort method ranked most to least important family needs or most to least supportive nursing behaviors during a relative's terminal cancer. The Likert-like scales required families to rate need statements along a continuum from "not important" to "very important." A qualitative discursive approach of content analysis was used to examine recurrent themes in the statements of needs and nursing behaviors that families identified as most and least supportive. Findings were compared within and across settings.

The results revealed several consistent findings across studies. The most important need of families related to having information about their dying relative. These families requested clear, honest information regarding the patient's condition, prognosis, and signs of imminent death. Also, assurance of patient comfort was of primary concern to the families.

Hull (1989) stated that findings from several hospital-based studies revealed that being near the dying patient was important to family members and that family members wanted to spend as much time as possible with their relatives.

Least supportive behaviors across settings included behaviors designed to encourage ventilation of the family's own feelings. This finding did not support the widely held view that encouraging ventilation of emotions is helpful to families.

In the hospital setting, Hull (1989) concluded that families desired the nurses' attention to be directed toward the patient and not the family, especially when the family viewed the nursing staff as busy and having limited time to spend with them. The families regarded other family members and friends as a more appropriate source of help for themselves.

Several limitations existed in the reviewed research. Hull noted that

> Limitations exist in design and methodology. Lack of control for several variables was of concern. Medical diagnoses differed across studies. The terminal period was not consistently defined; thus, the physical condition of the dying patients may have varied greatly, contributing to different levels of care responsibility and different family needs. (p. 790)

Hull concluded that additional research is needed and offered direction and practice implications. "Until a stronger scientific knowledge base is developed regarding family members during the terminal phase of a loved one's cancer, attention to these areas can assist nurses in supporting families through this difficult experience" (p. 791).

Holing (1986) conducted an exploratory, descriptive study to describe dimensions of the dying trajectory as perceived by the primary caregivers of recently deceased cancer patients. This research was undertaken because the family of a dying person assumes major involvement in the long-term home care of the patient with cancer, and there is little research about the impact of cancer on the family. The purpose of this study was to describe four theoretical dimensions of the dying trajectory as perceived by the primary caregiver of a recently deceased cancer patient, namely, duration, speed, shape, and intensity.

Glaser and Strauss's historical study (cited in Holing, 1986) of the dying process in hospitals was used as the theoretical framework. They defined the dying trajectory as the course of death as it is perceived by the participants (patient, family, and health care providers). Glaser and Strauss identified duration as a major component of the dying trajectory. Holing (1986) defined duration as the "length of time in days or weeks from the time the PCG initially perceived the person as dying to the actual date of death" (p. 30). If the patient, family, and health care providers have an actual and expected duration of living that are similar, then time allows for planning and organizing care. However, if the patient dies unexpectedly fast, both emotional and physical preparations of the patient and family may become misaligned.

Speed was defined as the perceived rapidity or quickness with which the trajectory moved. Speed was considered the subjective aspect of duration. Shape was defined as the graph of the dying trajectory indicated by the primary caregiver. Critical events were defined as experiences or events identified by the caregiver as especially important during the terminal phase of living. Intensity was defined as the perceived degree of physical or emotional energy expended by the PCG at the identified critical events in the trajectory. Holing's (1986) research attempted to describe periods of greatest intensity for the caregiver along the dying trajectory, including both the most joyful and most difficult periods.

A purposive sample was recruited from two community home health care agencies located in the Pacific Northwest. Fourteen caregivers were interviewed using an interviewer devised tool. This tool consisted of open-ended and direct questions. As a part of the interview, the caregivers were asked to identify experiences or events that stood out as especially important during the terminal phase of the patient's illness and to identify both stressful and joyful events. A six-point scale was used to quantify the amount of physical and emotional energy each critical event required. A six-point scale was used also to determine the caregiver's perception of the dimension of speed of the dying trajectory. Regarding duration, speed, and intensity,

the caregivers were asked how they perceived the situation and how they believed the patient perceived the situation. Data were analyzed using descriptive statistics and content analysis.

Findings related to the four variables of the dying trajectory were as follows: 50% of the caregivers stated that the patient lived about as long as they had expected (duration); 35.7% believed that the patient's approach to death moved very quickly or exceptionally quickly, the majority of caregivers believed that time passed more slowly for the patient than for themselves (speed); and 63.6% of the caregivers believed that the emotional energy required for the patient's care exceeded the physical requirement. Sixty-six critical events were identified by the caregivers. Related to stressful events, 42.9% of the caregivers identified some physical difficulty in providing care to the terminally ill patient. These difficulties included physical requirements, such as lifting and moving the patient and the caregiver's physical exhaustion from lack of sleep. Also identified were problems related to the pain involved watching the patient die and the emotional problems demonstrated by the patient, the difficulty of waiting for the patient's death, feelings of helplessness and guilt for not being able to do enough for the patient, and the loneliness and isolation associated with the provision of home care.

Related to joyful events, 57.1% of the caregivers described being pleased with the closeness they experienced with the patient. A total of 42.9% of the caregivers enjoyed the closeness and support of friends and family.

Holing (1986) concluded that different trajectories may require different coping mechanisms and may cause different management problems for caregivers and that it is the health care provider's responsibility to identify these problems and individualize patient/family care.

Holing's research revealed that individuals perceive events differently; therefore, no specific perception can be anticipated. This perception is unique to the caregiver and patient and constant adaptation is required. Hull (1989) concluded that families have specific needs and desire specific supportive nursing assistance during terminal illness home care.

The present research seeks to identify patient and caregiver perceptions, needs, supportive services, and adaptations that create problems in home care. The above noted studies validate that these problem areas exist. The problems may or may not play a role in the reasons for hospitalization of the hospice patient.

Chapter III

The Method

Utilizing a descriptive research design, this study examined the reasons community-based hospice patients require hospitalization. Polit and Hungler (1987) state that the purpose of descriptive research is to observe, describe, and document aspects of a situation. Descriptive studies are not concerned with relationships among variables. This type of research is especially valuable when little is known about the subject in question, such as reactions experienced or demonstrated by terminal patients or their primary caregivers that may interrupt hospice home care and require hospitalization.

Research Question

The major question this study sought to answer was what are the reasons, as cited by the primary caregiver, for the community-based hospice patient's hospitalization?

Limitations

The following were limitations of this study:

1. Limitation of this study to one geographical area prevents generalization to other geographical areas.

2. Limitation of participants to patients over 40 years of age prevents generalization to patients less than 40 years of age.

3. Limitation of participants to community-based hospice programs prevents generalization to other types of hospice programs.

4. The lack of established reliability and validity of the Stephens Survey of Hospice Patient's Primary Caregiver tool limits generalization of results.

5. The small sample size and lack of randomization may have resulted in a biased sample, preventing generalization to the larger population.

Setting, Population, and Sample

Setting. This research was conducted in a suburban community-based hospice program located in West Central Alabama. This agency served 129 patients in 1990. The average weekly census was 22.

Two full-time and three part-time registered nurses, one social worker, one chaplain, and an executive director are employed. A physician volunteers as medical director. This agency is Medicare certified.

The population in this West Central Alabama county is 137,541. The county consists of 1,333 square miles and has 37,907 rural residents and 99,634 urban residents (Bureau of Vital Statistics, 1989). Two hospitals are located within

the city limits, one of which is a regional medical center. Twenty-four hour emergency room services are available at both hospitals.

Sample and population. The accessible population included all primary caregivers of hospice patients 40 years of age or older who were hospitalized from January 1, 1990, to December 31, 1990, and who have since expired. The sample was one of convenience. Thirty letters of request for participation were mailed. Ten caregivers indicated a desire to participate. Seven caregivers did not wish to participate. No response was received from 13 caregivers. Fourteen caregivers were eliminated from the study due to such circumstances as the caregiver's out-of-state relocation after the patient's death and present illness of the caregiver. One potential subject was eliminated at the request of the participating hospice organization, and one caregiver was eliminated following the interview related to the inability to recall the needed information.

Plan for protection of human subjects. All subjects voluntarily participated in and were fully informed of the nature and benefits of this study. Confidential handling of all information and anonymity was maintained by reporting the results as group data.

Interview forms were coded and only the researcher had access to the caregiver's code number. The caregiver's code

number was stored in a locked file cabinet in the researcher's office.

Method of Data Collection

After receiving approval of the study from the Mississippi University for Women Committee on the Use of Human Subjects in Experimentation (see Appendix A), the researcher contacted the Board of Directors of a West Alabama hospice agency to gain permission to conduct this study. An agency consent form (see Appendix B) explaining the nature and purpose of the study and requesting permission was presented. Unanimous Board approval was granted and the request form was signed by the Board President in February, 1990.

The researcher then contacted the Executive Director of the hospice agency to request a list of all hospice patient caregivers meeting the pre-established criteria for participation. The researcher contacted the caregivers by letter to obtain written consent to participate. This letter also stated the purpose and described the research effort (see Appendix C). A self-addressed, stamped envelope was included to assist the caregiver to respond.

When this consent was obtained, the researcher contacted the caregiver by telephone and arranged an interview appointment, in the caregiver's home, to implement the Stephens Survey of Hospice Patient's Primary Caregiver tool (see Appendix D). The first question of this form

provided the primary caregiver with 11 physical symptoms to choose from that may have impacted the patient's hospitalization. For chosen symptoms, the primary caregiver was asked the frequency with which the choice impacted hospitalization. All interviews were tape-recorded. After the interview, the tapes were transcribed and carefully analyzed for clusters of themes related to the reasons for hospitalization. The tapes were destroyed at the conclusion of data analysis. Data were collected during the month of May, 1991.

As a part of this interview, the researcher asked the primary caregiver to sign an Authorization for Release of Medical Information form which authorized the researcher to review the patient's hospice medical record (see Appendix E). The researcher reviewed the medical record to note hospitalization dates and reasons for hospitalization, if noted, and this information was recorded on the Stephens Hospice Medical Record Information Form (see Appendix F).

Instrumentation. The Stephens Survey of Hospice Patient's Primary Caregiver tool and the Stephens Hospice Medical Record Information Form were developed by the researcher in conjunction with the review of the literature as no instrument was found that related to reasons for hospitalization of hospice patients. Therefore, validity and reliability have not been established. However, the instruments were reviewed by two nursing faculty members

experienced in hospice care to establish clarity and content. The instrument was assumed to have face validity within the context of this study. No pilot study was conducted.

The Stephens Survey of Hospice Patient's Primary Caregiver tool contained interviewer instructions, items to solicit demographic information on both the patient and primary caregiver, and three questions related to the reason(s) for the patient's hospitalization. The first question was comprised of 11 problems to which the caregiver responded "yes" or "no" and noted a frequency of the occurrence of these problems as it impacted on the patient's hospitalization. The second and third questions were open-ended and asked the reason(s) and circumstances preceding the patient's hospitalization.

The Stephens Hospice Medical Record Information Form solicited the primary caregiver's address, telephone number, and relationship to the patient. The patient's primary physician, patient's diagnosis, date of the patient's admission to the hospice, the date of death, and hospitalization date(s) were included also.

Data Analysis

Data to be examined were prepared using the fixed format. The data were checked for outliers and consistency. Percentages, frequency distribution, and means were used to

determine the reason(s) hospice patients required hospitalization.

The researcher and two nurse experts reviewed the transcribed interviews and determined four prevalent categories of information. The data were then re-analyzed and two major categories were determined.

Chapter IV

The Findings

The purpose of this descriptive study was to determine the reasons community-based hospice patients require hospitalization. Personal interviews were conducted with patient primary caregivers using the Stephens Survey of Hospice Patient's Primary Caregiver tool.

Description of Sample

The sample included nine primary caregivers who provided care to 9 community-based hospice patients. All patients were over age 40 years, required hospitalization in 1990, and have since expired.

Demographic data were compiled on the primary caregiver and patient. The age range of the primary caregivers was from 42 to 81 years, with a mean age of 64 years. This group was composed of 7 (78%) females and 2 (22%) males. Four (44%) of the caregivers were wives, 2 (22%) were husbands, 2 (22%) were daughters, and 1 (11%) was a sister.

The age range of the patients was from 42 to 96 years, with a mean age of 72.4 years. Five (55.6%) of the patients were female and 4 (44.4%) were male.

Of the 9 hospice patients, 2 (22%) had a diagnosis of lung cancer, and the remaining 7 (78%) had other sites of malignancies: liver, colon, parotid gland, uterus, prostate, bone, cervix, and sinus cavity. Three (33%) of the patients were treated by the same physician and 6 (67%) had other physicians.

The total number of hospitalizations for the 9 patients was 14. Five (56%) patients had one hospitalization, 3 (33%) patients had two, and 1 (11%) had three. Patients were in the hospice program from 12 to 93 days, with a mean stay of 43 days. Information from primary caregiver interviews revealed that 3 (33%) patients died at home while 6 (67%) died in the hospital.

Results of Data Analysis

The Stephens Survey of Hospice Patient's Primary Caregiver tool was used to collect data. The form addressed three questions:

Question 1. The first question allowed caregivers the opportunity to identify reasons for their loved one's admission to the hospital. The caregivers were asked to respond either "yes" or "no" to 11 possible problems and were asked how frequently these problems influenced the patient's hospitalization.

During their hospice stay, 5 (56%) patients experienced pain that influenced six hospitalizations. Therefore, pain was determined as the most common symptom that impacted

hospitalization. The researcher noted that 7 (78%) patients experienced more than one symptom, thus a combination of symptoms, which was complex nature, influenced the patient to be admitted to a hospital. No patients experienced problems with diarrhea or a comatose state. These data are presented in Table 1.

Table 1

Reasons for Hospitalization and Frequencies of Occurrence

Symptom	Yes	No	Frequency
Pain	5 (56%)	4 (44%)	6
Incontinence	1 (11%)	8 (89%)	2
Shortness of breath	1 (11%)	8 (89%)	1
Eating	2 (22%)	7 (78%)	2
Nausea and vomiting	2 (22%)	7 (78%)	2
Bleeding	1 (11%)	8 (89%)	2
Constipation	1 (11%)	8 (89%)	1
Family Stress	1 (11%)	8 (89%)	1
Other	8 (89%)	1 (11%)	11

Question 2. What was the reason or reasons for your loved one's admission to the hospital? The same reasons identified in Question 1 were again reflected by answers of the primary caregivers to Question 2.

Question 3. Question 3 asked the primary caregivers to describe the circumstances preceding their loved one's hospitalization. Only one primary caregiver understood the question. This caregiver responded immediately and appropriately without prompting by the researcher. Events were recalled for the weeks preceding her sister's hospitalization which impacted the hospitalization. The remaining eight primary caregivers were confused and required explanation as to the information being sought. Therefore, this information was eliminated from this study due to the gross biases introduced to the caregiver by the researcher.

Additional Information

Since interview technique was used, additional data were shared which amplified answers to Questions 1 and 2. An open coding method was used to determine common issues. These data were grouped into two categories.

Primary caregiver stressors/demands. The majority of caregivers noted stressors that impacted home care. Fear and exhaustion experienced by the primary caregiver were noted in the following comments:

It was just horrible. I couldn't handle it.

So tired I just couldn't handle it.

We didn't know what to do.

We were scared to death.

> She couldn't get up by herself. She couldn't walk. Every time she would get up she would go to the right.
>
> She wasn't able to walk from bedroom to bathroom by herself.
>
> And I wanted to keep her a lot longer but she got so sick, she got real dehydrated . . . I had to force her with all her food . . . with one of those tubes and that got to be real bad, I couldn't stand that.

A second stressor/demand was identified as 78% of patients experienced more than one symptom that impacted home care and hospitalization. One patient experienced increased pain, anorexia, and dehydration. Another experienced increased pain, ascites, and decreased urination, while another demonstrated a combination of symptoms of choking, eating difficulty, dehydration, and increased pain. This multiple symptomatology created stress for the primary caregiver as evidenced in the following comments:

> She wasn't able to eat and got weaker and weaker. She wasn't able to walk from the bedroom to the bathroom by herself. I didn't know what to do.
>
> She swole [sic] up . . and her urine blocked and she got real bad with the catheter. She didn't have an appetite at all and got real dehydrated. She started to vomit some. It was awful.
>
> The medications they were giving him were not really holding him. He had become real disoriented . . . He got real confused about things . . . He could not sleep . . . He was literally drowning in his own fluids . . . he was going down real bad . . . I couldn't hold him in bed.

Relationship with health care providers. Interview information revealed that the majority of primary caregivers experienced strong positive relationships with the participating hospice organization nursing staff and the patient's personal physician. The following quotes confirm this finding:

> Dr. R. is the kind of doctor that he will call, he doesn't wait for you to call him. That's something I love about him.
>
> (Hospice) . . . It was the grandest thing in the world.
>
> I would not have made it without her (hospice nurse) coming to the house here . . They were all so wonderful to us.
>
> They (hospice nurses) were here almost every day and they watched after her.
>
> I had some hospice volunteers that helped me.

Research data further revealed that the relationship between the primary caregiver and medical personnel influenced the patient's hospitalization. Four patients (44%) were admitted to the hospital at the recommendation of the attending physician. Two patients (22%) were admitted at the hospice nurse's recommendation. The remaining 34% were admitted at the recommendation of the primary caregiver. It is not known what consideration was given to the patient's wishes related to hospitalization. However, three primary caregivers (33%) stated that their loved one did not wish to be hospitalized and wished to remain at home. The following quotes substantiate these findings:

I know hospice had thought and I had thought we would stay at home . . . I was thinking that he needed help.

We took her back to the hospital to get built up.

He (M.D.) told me . . . "I think from what I see today that we should go ahead and put her in the hospital and start some IV's and do some checks and see."

The nurse came out and she advised us that it might be better to take him on to the hospital to see . . .

Chapter V

The Outcomes

Summary

This descriptive study was conducted to determine the reasons community-based hospice patients require hospitalization. The setting was a suburban community-based hospice program located in West Central Alabama. A sample of 9 primary caregivers participated. This group was composed of 7 (78%) females and 2 (22%) males, with an average age of 64 years. These caregivers provided care to 9 hospice patients over age 40 years who required hospitalization and had since expired. The average age of the patients was 72.4 years. These 9 patients had a total of 14 hospitalizations. Two (22%) patients had a diagnosis of lung cancer and the remaining 7 (78%) had various sites of malignancies.

During scheduled home interview visits, the researcher completed the Stephens Survey of Hospice Patient's Primary Caregiver tool to determine reasons for the patient's hospitalization(s). The researcher concluded that uncontrolled pain was the most common cause for the patient's hospitalization. Following further content analysis, two categories were determined that addressed

primary caregiver stressor/demands and relationships with health care providers.

Discussion

Since no other research specifically addressed reasons why hospice patients require hospitalization, there are no data that would either support or refute the findings of this study. However, Zimmerman (1986) identified the single most common reason for the hospice patient's hospital admission as inadequate pain control. Also, Watchtel et al. (1988) noted that pain was a common symptom among terminally ill hospice patients. The conclusion of these authors strengthened the inference of the present research finding.

The prevalence of pain in home hospice patients demonstrates the patient's self-care deficit. According to Orem (1980), in order to employ measures of care required to maintain well-being, the self-care deficit must be defined and addressed. Additionally, the prevalence of pain and its impact on hospitalization demonstrate the hospice patient's developmental self-care requisite. In order to prevent the occurrence of deleterious effects and subsequent hospitalization, the hospice nurse must be aware of ways to intervene, either on a partly compensatory, wholly compensatory, or supportive/educative level.

Christensen and Harding (1985), Rando (1984), and Morris et al. (1986) noted that increased or uncontrolled pain was a major factor in the precipitation of a family

crisis. Results of this current study indicate that the primary caregivers may have felt that the patient's pain was beyond their control and therefore developed feelings of inadequacy, fear, aggravation, and fatigue. This dilemma may have increased the primary caregiver's self-care demand so that they no longer were able to compensate for the patient's decline.

Although the present research identified uncontrolled pain as the most common cause of hospitalization, the primary caregiver's knowledge of or compliance with pain medications or previous teaching and/or instructions provided by the hospice nurse were not assessed. Knowing the primary caregiver's knowledge level and compliance with prescribed therapies may have revealed additional reasons for the patient's uncontrolled pain and subsequent hospitalization. Also, this researcher believes that the patient's uncontrolled pain precipitated additional stressors/demands of the primary caregiver that led to the patient being hospitalized.

Increased primary caregiver stressor/demands were identified and are supported by Stetz's (1987) research findings that the number one primary caregiver stressor is the demand of providing physical care for the patient. In the present research, primary caregivers experienced difficulties in ambulating and turning/positioning the patient as well as difficulties with other symptom control.

These findings validate the difficulty of managing the responsibilities of physical care, treatment regiments, and illness related changes for primary caregivers (Stetz, 1987). This researcher believes that as the patient becomes more dependent and the primary caregiver is less able to cope the primary caregiver may become overwhelmed with responsibilities which may impact the decision to hospitalize patients equally if not more than the patient's physical condition itself.

Patient symptoms of pain, shortness of breath, fever, nausea and vomiting, constipation, diarrhea, weight loss, and problems with eating and poor appetite were experienced by the hospice research patients. The present research found that as the patient's physical state deteriorated many of the above noted symptoms developed. Out of 9 patients, only 2 were admitted to a hospital for one specific symptom. The remaining 7 were experiencing multiple symptoms that contributed to hospitalization. There is clear evidence, through content analysis, that a temporal relationship exists between progressive increases in physical symptomatology and the parallel decline in function and quality of life related to terminal illness (Watchtel et al., 1988).

Increased emotional energy and physical difficulty in providing care to the patient substantiated Holing's (1986) findings related to stressful events of caring for the

terminally ill patient. Lifting and moving, primary caregiver exhaustion from lack of sleep, feelings of helplessness and loneliness, and isolation experienced by the primary caregivers in this research demonstrate these emotional and physical difficulties with home care.

Multiple symptomatology and physical deterioration noted in these hospice patients increased the patients' self-care demand. To meet these demands, according to Orem (1980), nursing care would be adjusted to meet the demands of the patient's increasing deterioration. Nursing care that began as supportive/educative with the patient and primary caregiver would advance to partly compensatory with nursing providing part of the patient care, to wholly compensatory in which the nurse provides total patient care due to the total disability of the patient. If nursing care was not adjusted, hospitalization was likely to occur. The present research did not examine the level of nursing care provided to each participant. However, strong positive relationships between the primary caregiver and hospice nursing staff/physician were identified.

The primary caregiver's satisfaction with nursing care and support is substantiated by Hull's (1989) research that concluded that families have specific needs and desire specific supportive nursing assistance during terminal illness. This researcher believes that a strong positive relationship related to the trust the primary caregiver had

with the hospice nurse and physician impacted hospitalization. Thus, when hospitalization was recommended for the patient, the primary caregiver complied, believing the placement was in the patient's best interest and medically warranted. However, the research tool used in this present study was inadequate in providing information related to the primary caregiver's feelings regarding these recommendations for hospitalization. Additionally, information was gathered after the patient's death so there was no opportunity to discover the patient's feelings regarding hospitalization.

Other problems existed with the Stephens Survey of Hospice Patient's Primary Caregiver tool and the sample of convenience. Although pain was the most common symptom that impacted hospitalization, primary caregivers were limited to 11 forced categories of symptoms, and the exact part that these symptoms played in the determination of the patient's hospitalization could not be determined. Also, Questions 2 and 3 were relatively inadequate in providing additional information as to a specific reason for hospitalization. Furthermore, the sample was selected from one hospice program, and the size was limited to hospice patients over the age of 40 years and their primary caregivers ($\underline{N}$ = 9). The 9 primary caregivers were residents of a small southern city and cultural, ethnic, and social status characteristics could have influenced their responses.

Conclusions

Based on data analysis, the researcher concluded that pain was the number one symptomatic problem and the number one reason that hospice patients were hospitalized. Since no previous research has determined this finding, results should be interpreted with caution. However, Zimmerman (1986) did postulate that inadequate pain control contributed to hospice patient's admission to the hospital. Further, two categories emerged from the interview sessions of this study which amplified the finding. Information in the first category demonstrated that caregivers undergo spiraling stressors and demands as the terminally ill patient experiences multiple symptomatology with corresponding physical deterioration. This conclusion is supported by Watchtel et al. (1988) who proposed that as symptomatology increased there was a parallel decline in function for terminally ill patients, and Holing (1986) who determined that an increase in emotional energy demand and physical difficulty in providing care created mounting stressors for the caregiver. The second category, relationship between the hospice nursing and medical staff, impacted the caregivers' decision to hospitalize the patient. Hull (1989) also concluded that caregivers have special needs and desire specific supportive assistance while providing care for loved ones with terminal illnesses.

The prevalence of pain in the hospice patients in this sample was defined by the researcher as a self-care deficit. Thus, adequate pain control demonstrates the hospice patient's developmental self-care requisite. The caregiver's increased stress level is considered a potential developmental self-care deficit. According to Orem (1980), in order to implement measures of care, self-care deficits must first be defined before the appropriate nursing system level is selected and operationalized.

Implications

These data suggest several possibilities for the Geriatric Nurse Clinician (GNC) in the hospice setting. Firstly, the GNC can increase the focus on pain assessment and management. This focus would include pain evaluation on each home visit and appropriate adjustments of pain medications and adjunct therapies. Also, the patient and primary caregiver's knowledge of and compliance with prescribed therapies should be noted. Secondly, existing patient and primary caregiver educational programs can be reviewed, evaluated, and redesigned to better manage patient's pain and associated physical symptoms. This review could identify problem areas with compliance therapy. Also, redesign based upon current treatment recommendations would assure the quality of the GNC's practice.

Initiating an interdisciplinary team approach to the management of patient pain certainly is within the realm of

the GNC. This approach would enhance more effective pain management and reduce the need for patient hospitalization. Further, using anticipatory guidance, the GNC could coordinate the patients' symptom development and physical deterioration and help design a plan of care that would more effectively manage problems by educating the patient/primary caregiver about expected outcomes.

As a part of a comprehensive data base, the GNC can evaluate the patient and primary caregiver, on admission and on subsequent visits, to determine stressors and demands that impact home care and influence hospitalization. Identifying and monitoring these stressors may lead to interventions that prevent hospitalization. Next, the GNC should evaluate the relationship between the patient/primary caregiver and health care providers to help establish collaboration in subsequent health care decisions. Also, the relationship between the patient and primary caregiver should be monitored to identify family crisis situations that may develop as a result of increasing care demands placed upon the caregiver.

Concerning nursing research, the GNC should conduct current nursing plan audits to assure proper management of patient pain. This information could reveal weaknesses in the plan of care and/or problems related to patient/primary caregiver compliance with prescribed nursing/medical therapies. To advance nursing education, the GNC could

conduct educational sessions with nursing personnel to assure pain is managed appropriately. Through a continuing systematic approach to pain management, the GNC could further apply and refine Orem's theory which offers direction to hospice nursing practice.

Recommendations

The following recommendations are made, based upon the findings of this study:

1. Conduct a study to develop a questionnaire which would more readily solicit information relevant to reasons hospice patients require hospitalization.

2. Conduct research related to stressors and demands experienced by hospice patients and primary caregivers.

3. Conduct research related to patient/primary caregiver teaching, compliance, and responses to pain management in hospice patients.

4. Replicate this study on a longitudinal basis from the patient's admission to the hospice program to the time of death to determine the occurrence of multiple symptomatology and resultant physical deterioration as it impacts hospitalization.

5. Replicate this study in a different geographic location with a larger sample representing multiple cultural and ethnic backgrounds and social status.

6. Conduct a study applying Orem's Self-Care Theory and Nursing Systems Theory to a hospice program.

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APPENDICES

APPENDIX A

APPROVAL OF COMMITTEE ON THE USE OF HUMAN SUBJECTS IN EXPERIMENTATION

MISSISSIPPI UNIVERSITY FOR WOMEN
Columbus, MS 39701

Vice President for Academic Affairs
P.O. Box W-1603
(601) 329-7142

March 21, 1991

Ms. Patricia M. Stephens
c/o Graduate Nursing Program
Campus

Dear Ms. Stephens:

I am pleased to inform you that the members of the Committee on Human Subjects in Experimentation have approved your proposed study on "Reasons Community-Based Hospice Patients Require Hospitalization."

I wish you much success in your research.

Sincerely,

Thomas C. Richardson
Vice President
for Academic Affairs

TR:wr

cc: Dr. Blow
Dr. Hill
Dr. Barrar
Dr. Rent

APPENDIX B

AGENCY CONSENT FORM

Agency Consent Form

Hospice of West Alabama
2123 9th Street
Tuscaloosa, Alabama 35401

Dear Sirs,

I wish to obtain your written permission to implement my research project concerning the reasons community-based hospice patients require hospitalization. This study is being conducted for partial fulfillment of required criteria for a Master of Science in Nursing degree at Mississippi University for Women, Columbus, Mississippi.

The purpose of this study is to determine the reasons community-based hospice patients require hospitalization. The primary caregivers for all expired Hospice of West Alabama (HOWA) patients over the age of 50 years who were admitted to the hospital in the year 1990 will be asked to participate in this study.

The Executive Director of Hospice of West Alabama will be asked to provide the researcher with the names of all patients meeting the above stated criteria and the name and address of their primary caregiver.

Each primary caregiver will be contacted by letter and asked to participate. This letter/consent form states the purpose of this study. Also, it ensures that confidential handling of data and anonymity will be maintained by the reporting of data as group data. The consent form states that the caregiver has the right to withdraw at any time from the study without consequences or prejudice to any future care they may request or require from Hospice of West Alabama. The caregiver's signature indicates voluntary participation and consent.

When written consent has been obtained, the researcher will interview the primary caregiver, in their home, using the Stephens Survey of Hospice Patient's Primary Caregiver tool. This tool consists of three questions relating to the reasons for the patient's hospitalization.

The benefits derived from this study would be to discover the reasons community-based hospice patients require hospitalization. This information could potentially lead to nursing interventions that could improve the quality of home care and possibly prevent some hospitalizations.

This study will be conducted at no cost to your institution nor to the participants.

Upon completion of the study, an abstract of the research will be available to you. If you have any questions or concerns, please contact Pat N. Stephens at (205) 349-1347.

Thank you for your time. Your prompt consideration of this research study in your institution would be greatly appreciated.

Sincerely,

Pat N. Stephens, BSN, RN
MUW Graduate Student

Your signature indicates permission for me to conduct this study.

Signature:_____

Witness:_____

Date:_____

APPENDIX C

PRIMARY CAREGIVER CONSENT FORM

Primary Caregiver Consent Form

_____
_____
_____

Dear _____:

My name is Pat Stephens. I am a part-time registered nurse working with Hospice of West Alabama. I would like to invite you to participate in a study I am conducting as a part of my graduate school nursing education at Mississippi University for Women in Columbus, Mississippi. I am pursuing a Master's of Science in Nursing.

We at Hospice of West Alabama are continually concerned with quality home patient care. Therefore, I am conducting this study to determine the reasons hospice patients are admitted to a hospital setting. The benefits of the study would be to aid me to know the reasons hospice patients enter the hospital. I hope that knowing these reasons will help me and other nurses to provide better home nursing care to hospice patients in the future and possibly prevent some patients from having to be readmitted to a hospital if they so desire.

You were selected to participate because you provided care to a hospice patient who was admitted to the hospital in the year 1990. All persons, such as yourself, have been asked to participate.

If you choose to participate, I will meet with you in your home. I will ask you three questions concerning your loved one's hospitalization. This interview will take about one hour to complete. The interview will be tape-recorded to help me include all the information you provide. This tape will be returned to you or destroyed, whichever you choose, at the end of this study.

Any information you provide will be reported as group data and in NO way will your or your loved one's names be identified. I am the only person who will have access to the information you provide. There is no cost to you or your family for participating in this study.

You have the right to withdraw at any time, up to data analysis, from this study without prejudice or decreases in any treatment or care you may request or require from Hospice of West Alabama.

I will contact you by telephone in the next 10 days. If you have any questions before I contact you, please feel free to call me at (205) 349-1347.

Sincerely,

Pat N. Stephens, BSN, RN

Consent Form

You are making a decision whether or not to participate. PLEASE RETURN THIS FORM IN THE ENCLOSED ENVELOPE WITHIN 10 DAYS. Thank you.

_____ Yes, I wish to participate.

_____ No, I do not wish to participate.

_____ _____

Signature Date

_____

Relationship to Patient

APPENDIX D

STEPHENS SURVEY OF HOSPICE PATIENT'S PRIMARY CAREGIVER

Stephens Survey of Hospice Patient's

Primary Caregiver

Interviewer Instructions:

ALL INFORMATION IS TO BE TAPE-RECORDED.

1. Complete this form for each hospitalization required by the patient.
2. Read the questions to the primary caregiver exactly as it appears on this form.
3. Instruct the primary caregiver to respond based on their feeling at the time of the patient's hospitalization, not on their present feelings.
4. Assure the primary caregiver that there are no right or wrong answers.
5. Include all information offered by the primary caregiver. Do not summarize or paraphrase.
6. Remind the primary caregiver that confidentiality will be maintained in the handling of this information and that the information will be reported as group data.

Stephens Survey of Hospice Patient's

Primary Caregiver

Code #_____

Primary Caregiver Information:

Age:_____ D.O.B.:_____ Sex:_____

Relationship to Patient:_____

Patient Information:

Age:_____ D.O.B.:_____ Sex:_____

Hospice Admitting Diagnosis:_____

_____

Primary Physician:_____

Date Admitted to Hospice:_____

Date of Death:_____

Number of Hospitalizations Since Admission to Hospice:

_____

Date of Hospitalization(s):_____

_____

1. Did any of the following problems influence your loved one's admission to the hospital? How often?

Problem	Yes	No	Frequency
a. Pain			
b. Incontinence			
c. Shortness of breath			
d. Eating problems			
e. Nausea and vomiting			
f. Bleeding			
g. Constipation			
h. Diarrhea			
i. Comatose state			
j. Family stress			
k. Other			

2. What was the reason or reasons for your loved one's admission to the hospital?

3. Describe the circumstances preceding your loved one's hospitalization.

APPENDIX E

AUTHORIZATION FOR RELEASE OF MEDICAL INFORMATION

Authorization for Release of

Medical Information

Attention:

Hospice of West Alabama
2123 9th Street
Tuscaloosa, Alabama 35401

I hereby authorize and request you to furnish to

Pat N. Stephens, BSN, RN
810 Overlook Road North
Tuscaloosa, Alabama 35406

any and all information you have regarding the medical records of

Name:_____

Date of Birth:_____

Date of Death:_____

_____
Authorized Signature

_____
Relationship to Patient

Witness:_____

Date:_____

APPENDIX F

STEPHENS HOSPICE MEDICAL RECORD INFORMATION FORM

Stephens Hospice Medical Record

Information Form

Code #_____

Primary Caregiver's

Address:_____

Telephone:_____

Relationship to Patient:_____

Patient's Primary Physician:_____

Patient's Diagnosis:_____

_____

Date of Patient Admission to HOWA:_____

Date Patient Expired:_____

Hospitalization Dates:_____

_____